



Pediatric Palliative Care Stakeholder Meeting
November 29, 2006, 10:00 A.M. – 3:00 P.M.
Minutes

Welcome

Marian Dalsey, M.D., M.P.H.
Chief, CMS Branch
Rene Mollow, R.N., M.S.N.
Associate Director for Health Policy

Introductions and Housekeeping

Sheryl Gonzalez, R.N., B.S.N.
CMS Branch

History of Pediatric Palliative Care Services in CA

Margaret Clausen, Director
CA Hospice and Palliative Care Association

Remarks from Children's Hospice and Palliative Care Coalition (CHPCC)

Lori Butterworth, CHPCC
Devon Dabbs, CHPCC

Beginning the Process

Marian Dalsey, M.D., M.P.H.
[See Powerpoint Presentation]

- Review of Statute, signed September 2006, effective January 2007: those under age 21 and CCS eligible. Waiver to be submitted to Federal CMS by 1/1/08 and up to 12 months thereafter before waiver is approved and becomes effective. Allows funding of 3 DHS positions to help develop this project. DHS Children's Medical Services Branch/CCS program to develop waiver in collaboration with the Medi-Cal Waiver Unit with input from stakeholders. Children's Medical Services Branch to oversee implementation, management, and evaluation of waiver. Local county CCS programs will authorize services. Group to define who will be eligible, what services are covered, geographic areas to be covered, and data and evaluation methods and partners.
A listserve will be set up on the Pediatric Palliative Care website at www.dhs.ca.gov/pcfh/cms/ppc/. Information and progress of the waiver process will be available on this site. To sign up for the listserve and provide feedback, send correspondence to Pediatric Palliative Care e-mail address (ccsppc@dhs.ca.gov).
- Description of Current System
- Other State's Efforts: Florida is only state with an approved waiver (about 200 children enrolled in plan); Colorado has program for children with life expectancy of less than twelve months;

- CCS: Current enrollment = 172,000. Of those, CCS estimates there may be up to 16,000 that would benefit from the waiver, including: 4400 children with cancer, 600 with CF, 300 with cardiomyopathy, 2000 with spina bifida, 1900 with severe cardiac conditions, 300 with ESRD, 300 with respiratory failure
- Current Constraints
- While waiver development is in process, CCS program will develop policy letter on services that may be authorized now. CCS currently cannot authorize respite or hospice services.

Interaction Between State and Advisory Committee

Rene Mollow, R.N., M.S.N.

- May have some constraints based on law. DHS looking for engagement in how benefits are constructed in CA.
- Conceptual framework needs to be agreed to by federal government.
- Discussion of Department split.

Overview of Waiver Development Process

Barbara Lemus

Chief, Waiver Analysis Section, Medi-Cal Policy Division

- DHS is the single state Medicaid agency responsible for the Medi-Cal program.
- Waiver unit within DHS has 2 roles: 1) advocacy; and 2) technical assistance
 - Acts as liaison between the State and the federal CMS
 - Manages waiver application/renewal processes
 - Ensures compliance with federal requirements
- State CMS to operate and monitor the Pediatric Palliative Care Waiver
- Description of various types of waivers
 - 1115 – Demonstration waivers
 - 1915(b) – Freedom of Choice waivers
 - 1915(c) – Home and Community Based Services (HCBS) waivers
- 1915(c) – HCBS waiver recommended for CA by federal CMS
 - Designed to offer safe and appropriate home care to individuals in lieu of care in an institution
 - Allows State to design waiver program to address needs of target population
 - Allows federal CMS to waive statewideness, comparability, and income & resource standards
- HCBS requirements:
 - Institution level of care (e.g. nursing facility, hospital, etc.)
 - Enrollment limit or cap
 - Assurances (e.g. health & safety, fiscal accountability, etc.)
 - Services must be different from State Plan services (in scope, amount, or duration)
 - Cost neutrality: cost to federal govt. with waiver must be \leq than cost without waiver
- HCBS Waiver Development Steps
 - Takes 1 yr. to 18 months
 - Consultation with federal CMS throughout process
 - Stakeholder input during development and comments on draft application

Guidelines for Pediatric Palliative Care Discussion

Lori Butterworth and Devon Dabbs, CHPCC

- The goal: To prevent and relieve suffering and to maximize quality of life for children of all ages and their family members/support systems (World Health Organization, 1998)
- Suggestions to consider:
 - National Consensus Projects, which has 8 established domains constituting palliative care
 - National Quality Forum soon to release standards for palliative care
 - Federal CMS has approved the CHI PACC model (chionline.org)
 - Florida and Colorado using CHI PACC model
 - For waiver eligibility criteria, Federal CMS requires patient to be at risk of meeting institutional Level of Care (Nursing Facility, Hospital, ICF/MRP)
 - Not enough trained providers

Brainstorming Discussion of Pediatric Palliative Care Concepts

Joleen Heider, M.S., R.D

Chief, Statewide Programs Section, CMS

Geographic Location

Care coordination considerations

Schools (DNR)

Rural setting

Pilot sites

Providers

CCS/MediCal provider shortages

Child life specialist

Chaplain

Mental health

Bereavement Criteria

Quality care

Education of providers

Benefits

Care coordination

Plan goals

Assistance with transportation

Service Delivery model

Models

National Project Quality Care

Standards of practice for Palliative Care

CHI PACC Model

Service delivery

Population

Family willing to participate

Size of population

Cost of care (high need)
Outcome data
Qualitative surveys
Statistician
Alternative settings

Barriers

Children in managed care
Requirements for institutional LOC
At some point during illness
Limited providers in the community
Hospice limitations with federal requirements
MediCal rates

Medical Eligibility

Defined ICD9 codes
Allocation for pediatric variations
Consider LOC issues
Ends stage increases cost
Category of family need
Consider other states' eligibility criteria
Available services consistent through illness

Eligibility

Level of child's functioning
Technology needs
Appeal criteria

Benefits

Availability of 25 hr access
Focus on families including children
Training of caregivers
Accessibility
Hospice core elements: MD, SW, RN, Chaplain, RD, CHHA, PT/OT, volunteers
Bereavement one year after death
Transitions/links
Case management

3 Subcommittee groups formed (with participant sign-ups)

Service delivery model, includes benefits
Outcome data
Eligibility

Wrap-up and Next Steps

Joleen Heider, M.S., R.D.

- 3 Subcommittee groups to begin meeting in January 2007
- Subcommittees to report back to general stakeholder group
- Next stakeholder meeting projected for April 2007